



KidneyCancerAssociation™

ANNUAL REPORT 2020

Strong Alone. Unstoppable Together.®



NOV 1, 2019 – OCT 31, 2020

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A Note from Our CEO

We began 2020 with high hopes of achieving more for the kidney cancer community than ever before.

Through a pandemic that continues to impact people across the world, I'm proud that we've remained committed to bringing our mission into the homes of patients through resources and services that empower them to live better with kidney cancer.

This was the first full year in which we rolled out innovative new programs after a year of setting the stage. Already, we've seen the Patient Navigator Program help connect people like Kayla (page 10) with the resources her family needed through her cancer journey and how the Just Diagnosed Toolkit empowered Mike (page 9) to open up to his doctor.

As we mark the KCA's 30th anniversary, stories like these remind me how important it is to keep patients and families at the heart of all we do—just like our founder, Eugene P. Schonfeld, a patient and fierce advocate, did.

In my career, it's been an honor to stand alongside people through their cancer journeys. Their daily courage inspires me to press on, to find strength in numbers, and to explore all the ways we can move the needle in kidney cancer.

Thank you for joining us, for supporting this community, and for being part of our efforts.



Sincerely,

A handwritten signature in black ink that reads "Gretchen".

Gretchen E. Vaughan

President and CEO, Kidney Cancer Association

A Note from Our Board Chair

One of the greatest gifts of being a doctor is seeing firsthand how advances in medical research make a difference in the lives of the patients and families in my care.

In the past 30 years, the KCA has awarded over 50 research grants that contributed to changing the landscape of kidney cancer care. I'm very proud we have strengthened our focus on supporting groundbreaking kidney cancer research. This year—for the second year in a row—we supported established and promising scientists with \$1.3 million in grants. Now, we're seeing the fruits of those projects in completed research that not only moves the science forward but inspires new and different minds to tackle the problems people with kidney cancer face.

This means, in addition to developing resources that help patients today, the KCA is pursuing a brighter future for the whole kidney cancer community. We have accomplished so much in the last 30 years, and I am hopeful of what we can accomplish together in the years to come.

It has been exciting to watch Gretchen E. Vaughan, now gaining even more momentum in her second year as President and CEO, lead the KCA through this transformation into a more patient-focused and science-driven organization.

Having seen the prospects for kidney cancer patients change for the better over the past 30 years, I'm thrilled for all of us to carry this momentum forward and deliver an even higher standard of research, care, and hope to the families who are counting on us.



Sincerely,

Dr. Christopher G. Wood

*Chair, Board of Directors, Kidney Cancer Association
MD Anderson Cancer Center*

Board of Directors

Lisa Alderson

*Co-Founder and CEO, Genome Medical, Inc.
San Francisco, California*

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*Bukowski Consulting LLC
Emeritus Staff, Cleveland Clinic Taussig
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*Operations Program Manager, Apple Inc.
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*Vice President of Clinic Operations,
Optum Care
Los Angeles, California*

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*Retired, formerly a partner of K&L Gates LLP
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*Professor of Urology and Deputy Chairman,
MD Anderson Cancer Center
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Laura Wood, RN, MSN, OCN

*Research Coordinator, Cleveland Clinic
Taussig Cancer Center
Cleveland, Ohio*

Ruben Ybarra

*Installation Lead/Project Engineer,
Poseidon Services Inc.
Houston, Texas*

Our Mission and Vision

The Kidney Cancer Association (KCA) was founded in 1990 by a small group of patients and doctors in Chicago, Illinois, and has grown into an international non-profit organization. The KCA promotes scientific advances through two annual research symposiums and a robust grant program, participates in legislative advocacy, and seeks to be the trusted source of education and resources for patients, caregivers, and all those impacted by kidney cancer.

OUR MISSION

is to be a global community dedicated to serving and empowering patients and caregivers, and leading change through advocacy, research, and education.

OUR VISION

is to be the universal leader in finding the cure for kidney cancer.



Kidney Cancer Impact

Most people diagnosed with kidney cancer, also known as renal cell carcinoma, are between ages **65–74**.¹

Kidney cancer is about **twice** as common in men than in women.¹

¹ American Cancer Society, 2020.

² SEER Cancer Statistics Review, 1975–2017, National Cancer Institute, 2019.



75.2% 5-year survival rate (2010–2016)²



There are **558,023** people living with kidney and renal pelvis cancer²



73,750 estimated new cases of kidney cancer in 2020²

Research

THINK TANK: COALITION FOR A CURE

The KCA is committed to improving outcomes for and empowering patients with kidney cancer. In 2019, we brought together a team of clinicians, researchers, drug companies, and patient advocates to identify the major challenges in kidney cancer care and prioritize possible ideas to overcome them. **A summary of those discussions was published in *Clinical Genitourinary Cancer* (doi.org/10.1016/j.clgc.2020.10.005).** Continuing the momentum, in November 2020, over 17 leading institutions were brought together to lay the collaborative framework around specific projects stemming from that inaugural session. We hope these upcoming initiatives and educational programs will partner researchers, clinicians, industry, and patients together to increase detection and improve treatment, simplify clinical trial matching, and optimize disease-free survival for kidney cancer.



Q&A WITH DR. PAVLOS MSAOUEL

Dr. Pavlos Msaouel is a clinician and cancer biologist at MD Anderson Cancer Center in Houston, Texas, and a 2018 KCA Young Investigator Award recipient.

Q: How would you say your research project contributed to the field?

My Kidney Cancer Association Young Investigator Award focused on the biology of the cytoskeleton inside the cells of rare kidney tumors. We started testing our specific hypotheses and were led to unexpected findings, some of which are potentially relevant to all kidney cancers. Rare kidney cancers in many ways are “Rosetta Stones” for cancer biology.

Q: What was the outcome of your research project?

From humble beginnings, and through the passionate advocacy of my mentor Dr. Nizar Tannir, we built a team of clinicians, translational and basic researchers, bioinformaticians, and biostatisticians, as well as a pipeline of co-clinical and clinical trials that support our discoveries. It takes a village to generate impactful research and our research project funded by the Kidney Cancer Association helped establish that team. This subsequently led to our recent manuscript in *Cancer Cell* describing the molecular hallmarks of renal medullary carcinoma.

Research: The KCA Presents Grants Totaling \$1.3M

The KCA grants two Advanced Discovery Awards (ADA) and four Young Investigator Awards (YIA) —a total of \$1.3 million in funding— to researchers from around the world who are working to advance early detection of and discover new treatments for kidney cancer.

Introduced in 2019, the ADAs promote collaboration between established clinicians and basic scientists on new research that will make an immediate impact in kidney cancer. YIAs encourage promising researchers in urology and clinical oncology who are planning to pursue an investigative career in kidney cancer.

“Supporting research is integral to achieving our vision to be a leader in finding a cure for kidney cancer. We are excited by the winning research projects and hope to see these researchers’ efforts come to fruition so we can all learn more about how to best manage this disease.”

Dr. Christopher G. Wood

*Chair, KCA Board of Directors
MD Anderson Cancer Center*

2020 ADVANCED DISCOVERY AWARD (ADA) RECIPIENTS



Heather Christofk, PhD
Brian Shuch, MD

University of California, Los Angeles

Topic: Targeting asparagine dependence in renal cell cancer



Haifeng Yang, PhD

*Thomas Jefferson University,
Philadelphia, Pennsylvania*

William Kim, MD

University of North Carolina at Chapel Hill

Topic: Investigating the anti-tumor efficacy of a STING agonist on PBRM1-deficient ccRCC tumors

2020 YOUNG INVESTIGATOR AWARD (YIA) RECIPIENTS



Chiara Di Malta, PhD

Andrea Ballabio, MD (Mentor)

*Telethon Institute of Genetics and Medicine,
Pozzuoli, Italy*

Topic: Exploiting the potential of MiT/TFE factors inhibition to treat inherited kidney cancers



Brandon Manley, MD

John Koomen, PhD (Mentor)

*H. Lee Moffitt Cancer Center and Research
Institute, Inc., Tampa, Florida*

Topic: Investigation of the aberrant epidermal growth factor receptor splicing proteome to determine drug repurposing strategies for ccRCC



Frank M. Mason, PhD

W. Kimryn Rathmell, MD, PhD (Mentor)

*Vanderbilt University Medical Center,
Nashville, Tennessee*

Topic: Therapeutic vulnerability of SETD2 mutant RCC



Ritesh R. Kotecha, MD

Robert J. Motzer, MD (Mentor)

*Memorial Sloan Kettering Cancer Center,
New York, New York*

Topic: HLA evolutionary diversity – a population specific biomarker for kidney cancer immunotherapy

“For 30 years, the KCA has been supporting scientific advancements through research, and it’s an honor to be part of the work of so many incredible researchers working together for one goal.”

Gretchen E. Vaughan

President and CEO, Kidney Cancer Association

Patient Resources

- Just Diagnosed Toolkit
- Patient Navigator Program
- Unstoppable Together Newsletter
- Patient Video Library
- KCA Blog
- Ask Ina®: The Intelligent Nutrition Assistant
- KCA's Online Support Community
- Ask the Experts

Just Diagnosed Toolkit

This toolkit aims to help patients and their families make important decisions about their care when they are overwhelmed from just receiving a kidney cancer diagnosis.

→ kidneycancer.org/just-diagnosed/

"My doctor joked that he didn't know that all he needed to do to get me to talk was point me in the direction of the KCA. Because of the KCA's Just Diagnosed Toolkit on your website, I felt like I finally knew what questions to ask and how to ask them. I left knowing more about my own cancer after one meeting than I had in months."

Mike

Living with kidney cancer



Patient Navigator Program

The Patient Navigator Program was launched July 2020 as a place for anyone affected by kidney cancer to receive personalized information, resources, education, and support. A dedicated Patient Liaison responds to inquiries from the kidney cancer community about a recent diagnosis, how to find an expert, questions about treatment, or finding support, in a compassionate and empathetic way.



Rosemary Chustak
KCA's Patient Liaison

→ *Contact the Patient Liaison today!*
patients@kidneycancer.org or call 1-800-544-3KCA

“On top of becoming the mother of a baby... I had a cancer diagnosis. [My husband] had to quit his job to take care of both the baby and me during this hard time. I am grateful for the KCA’s Patient Liaison, Rosemary, and am so appreciative of the support received through the KCA’s Patient Navigator Program.”

Kayla

Living with kidney cancer

Unstoppable Together Newsletter

The Unstoppable Together Newsletter includes updates from the KCA, stories from the KCA blog, and important news for the whole kidney cancer community.

→ Sign up for our newsletter: secure.kidneycancer.org/np/clients/kca/survey.jsp?forwardedFromSecureDomain=1&surveyId=6

Patient Video Library

Patients, caregivers, and family members can access short videos that answer common questions about kidney cancer answered by kidney cancer specialists.

→ kidneycancer.org/video-library/

KCA’s Online Support Community

Inspire.com is a place for people living with and affected by kidney cancer to connect and learn from each other.

→ inspire.com/groups/kidney-cancer-association/

KCA Blog

Check out the KCA blog for patient stories, kidney cancer news stories, conference highlights and interviews with key KCA stakeholders.

→ kidneycancer.org/blog

Ask Ina®: The Intelligent Nutrition Assistant

Ina® helps people with cancer eat healthy, manage nutrition-related treatment side effects, and stay well-nourished throughout their treatment and beyond.

→ kidneycancer.org/ina-by-savor-health/

Ask the Experts: Common questions about kidney cancer and COVID-19

In addition to the KCA’s COVID-19 information and resources page, we tackle the most important COVID-19 questions directly from the kidney cancer community. Kidney cancer experts weigh in and address these kidney cancer-specific COVID-19-related concerns.

→ kidneycancer.org/ask-the-experts-common-questions-about-kidney-cancer-and-covid-19/

A patient called the KCA’s Patient Navigator Program. She was frustrated because she was unable to reach her specialist and was concerned with how the lack of communication might affect her treatment. Rosemary, our Patient Liaison, discussed the importance of asking the right questions at each appointment, some specific questions she could ask to address her current concerns and provided her the Questions to Ask Your Doctor tip sheet for future reference. The patient was more equipped and empowered with this 1-on-1 assistance!

Advocacy

Since 2014, the Kidney Cancer Association has been part of the Defense Health Research Consortium (DHRC), which works collectively to protect and enrich the Congressionally Directed Medical Research Programs (CDMRP) under the Department of Defense.

This year, we took the KCA's most active role yet, lobbying our elected representatives in Congress to increase funding for kidney cancer through the CDMRP. Because of these lobbying efforts, the DHRC with support from the KCA and other collaborative organizations secured \$40 million in funding specifically for kidney cancer research!



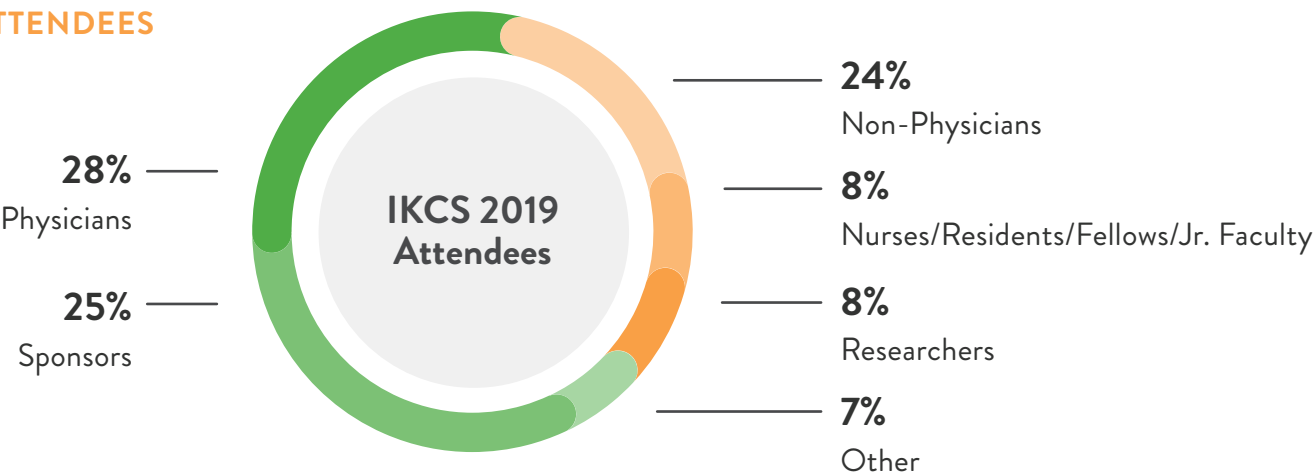
The DHRC with support from the KCA and other collaborative organizations secured \$40 million for kidney cancer research!

Education: KCA International Kidney Cancer Symposium

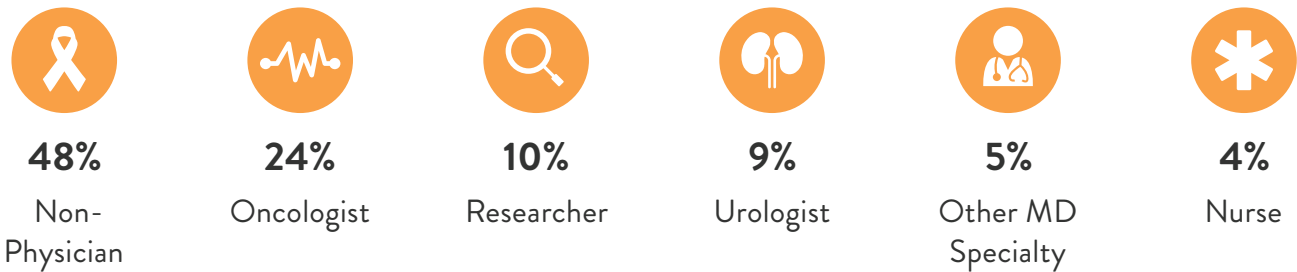
The KCA kicks off every fiscal year with our International Kidney Cancer Symposium (IKCS). IKCS 2019 was held on November 15-16, 2019 and welcomed more than 450 registered attendees from multiple disciplines. This annual event, along with the KCA's European International Kidney Cancer Symposium (EIKCS) held each spring, is an opportunity for physicians, researchers, academics, and industry professionals from across the globe to join together and exchange ideas which will direct the future of kidney cancer research and treatment in the ultimate pursuit of a cure.

Unfortunately, due to the ongoing COVID-19 pandemic, the KCA had to cancel EIKCS 2020.

ATTENDEES



SPECIALTIES



REGIONS



IKCS 2019 Highlights



MIAMI, FLORIDA | NOVEMBER 15-16



New CME Programming for HCPs

The KCA launched Certified Medical Education (CME) programming on July 30, 2020, to further the education of healthcare professionals interested in advancing their clinical knowledge of kidney cancer in ways that positively impact patient care. In just three months, **57 clinicians earned CME credits.**



POWERED BY

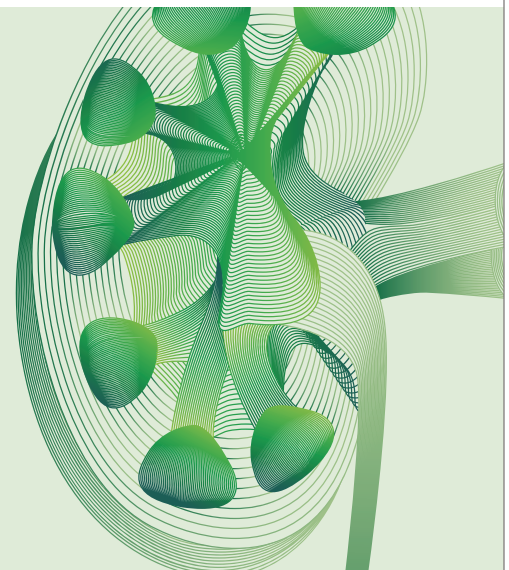
KidneyCancerAssociation™



The
France
Foundation

CONTEMPORARY TOPICS IN

Renal Cell Carcinoma



Awareness

The KCA continues to reach kidney cancer communities across the globe, specifically through awareness campaigns. Our favorite this year was our 74k Challenge.



Nearly 74,000 people were estimated to be diagnosed with kidney cancer in 2020. This staggering statistic inspired the Kidney Cancer Association to launch our first and largest community fundraising initiative to raise hope, awareness, and funds that will directly impact kidney cancer research. The 74K Challenge kicked off on June 18, 2020, in celebration of World Kidney Cancer Day. The goal was to inspire people to get active during the month of June and raise awareness for kidney cancer. Our goal was to raise \$74,000. The KCA matched donations dollar-for-dollar, and 100% of proceeds supported kidney cancer research. The outpouring of support, creativity, and community was incredible!

In total, **74 individuals** participated in the 74K Challenge, including six teams spanning from coast to coast. Thanks to **377 generous donations**, the 74K Challenge met its fundraising goal and spread awareness about kidney cancer far beyond what can be quantified.





Betsey Utter + Friends

7.4-Mile Walk



Holden Shirley + Neighborhood

74-Square Hopscotch



Ryan Natzke + Family

Throw 74 Hammers (Frisbee)

AND THIS IS ONLY THE BEGINNING...

Since the 74K Challenge, more people have come up with creative ways to raise money and awareness for kidney cancer research. A popular video gamer out of Atlanta who goes by the name “The Sarge”, created a fundraising page with the KCA’s community fundraising tool. Another fundraiser and fitness instructor hosted outdoor workout classes inviting participants to donate to her fundraising page. Still others have used the KCA’s tool to raise money in honor or memory of a loved one, to enjoy a virtual happy hour while giving back, or to dedicate their birthday or anniversary toward supporting the KCA.



The 74K Challenge is
all about getting active and
having fun while raising money
for kidney cancer research!

2020
74K
CHALLENGE

Our Impact This Year



Our Patient Liaison assisted **84** people from **19** states and **3** countries in just **4** months



1,093 people explored the new Just Diagnosed Toolkit in just 3 months



Provided over **60** hours of kidney cancer Certified Medical Education credits (CME) to medical professionals



8 patients and caregivers became founding members of our Patient and Caregiver Advisory Council



74 participants in the 74K Challenge collected **377** generous donations



Funded **\$1,300,000** in grants for groundbreaking kidney cancer research



Debuted a fresh new user-friendly website



Launched **8** new resources for the kidney cancer community



Our online support community reached over **3,000** people spanning **9** countries



Shared **82** stories about people from our kidney cancer community



Advocated to boost federal funding for kidney cancer research to **\$40** million



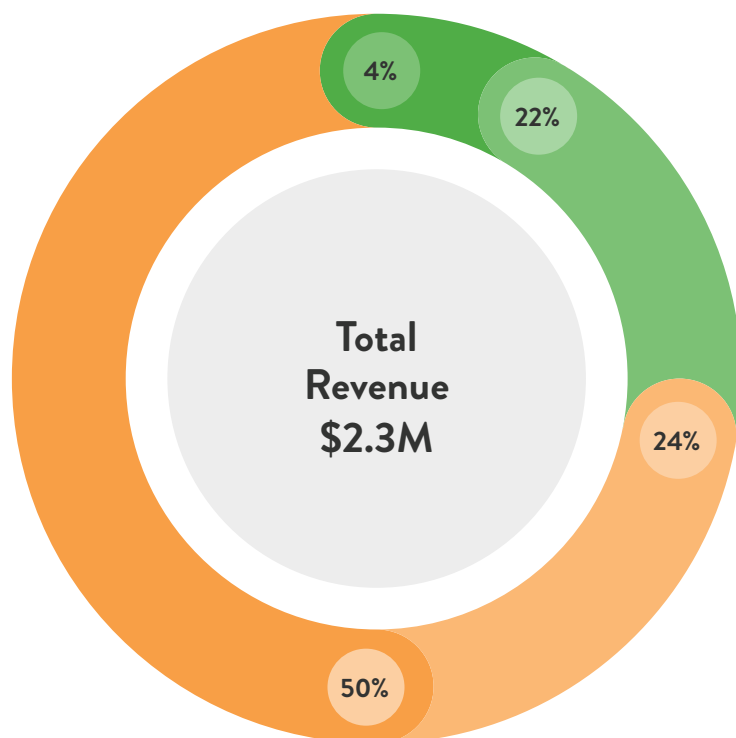
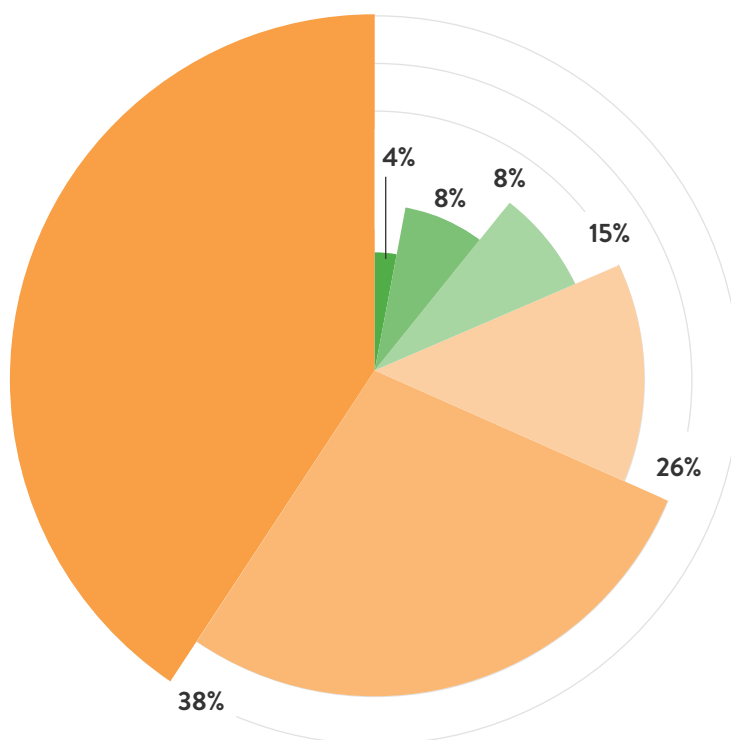
Celebrated **30** years of the KCA!

Financials

TOTAL EXPENSES

Cost distribution by category
(numbers in thousands)

Category	Expense
● Research	\$1,503
● Education	\$988
● Patient Resources	\$582
● Fundraising	\$326
● General and Administrative	\$317
● Advocacy	\$158
Total Expenses	\$3,900



TOTAL REVENUE

By sources (numbers in thousands)

Source	Revenue
● Educational Symposium Sponsorship and Registration	\$1,126
● Investments	\$556
● Individual Giving	\$512
● Corporate Giving	\$71
Total Revenue	\$2,265

*Figures presented are accurate as of 10/31/2020 and may be slightly adjusted during final year-end financial review and audit.



Statement of Financial Position

ASSETS

Current Assets	2020	2019
Total Bank Accounts	\$5,937,208	\$8,754,980.00
Total Accounts Receivable	\$337,226	\$8,000.00
Other current Assets	\$20,315,878	\$19,904,598.00
Total Current Assets	\$26,590,313	\$28,667,578.00
Total Other Assets	\$36,000	\$36,000.00
Total Fixed Assets	\$18,033	-
Total Assets	\$26,644,346	\$28,703,578.00

LIABILITIES AND EQUITY

Liabilities	2020	2019
Accounts / Grants Payable and Accrued Expenses	\$1,068,769	\$1,133,983.00
Other Liabilities	\$861,630	-
Total Liabilities	\$1,930,399	\$881,630.00
Total Equity	\$24,713,947	\$27,569,595.00
Total Liabilities and Equity	\$26,644,346	\$28,703,578.00

Thank You KCA Family

Since it was founded 30 years ago, the Kidney Cancer Association has been dedicated to serving patients, caregivers, families, and friends affected by kidney cancer. As we celebrate this milestone, we want to set new goals and dreams for what we can accomplish. Through service to you and a focus on groundbreaking science, we believe we can transform care, drastically decrease mortality rates, and—ultimately—find a cure for kidney cancer. Our promise is to conduct our work with integrity, with passion, and with impact.

Thank you for being part of our KCA family. We are strong alone, but unstoppable together.

Sincerely,

The KCA Team



**Thank you for another
unstoppable year together!**

The KCA Team

Gretchen E. Vaughan

*President & CEO
Houston, Texas*

Kendall Pace Monroe, MPPA

*Chief Advancement Officer
Houston, Texas*

Susan Alanis

*Director of Gift Processing
Houston, Texas*

Radha Chitale

*Director of Communications
Washington, D.C.*

Rosemary Chustak

*Patient Liaison
St. Louis, Missouri*

Courtney Firak, MPH

*Senior Director of Programs and Partnerships
Chicago, Illinois*

Jenny Fitzgerald

*Accountant
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Houston, Texas*

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Houston, Texas*

Sallie McAdoo, MS, CGC

*Medical Director
Houston, Texas*

Angela Randolph

*Director of Operations
Houston, Texas*

Stephanie Shirley

*Director of Advancement Services
Harrisburg, Pennsylvania*







KidneyCancerAssociation™

The Kidney Cancer Association is a global community dedicated to serving and empowering patients and caregivers, and leading change through advocacy, research, and education in order to be the universal leader in finding a cure for kidney cancer.

KIDNEYCANCER.ORG

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